HOPE • COMMUNITY • SUPPORT • RESOURCES

WISCONSIN PARKINSON ASSOCIATION MAGAZINE

ISSUE NO. 119 | 2025

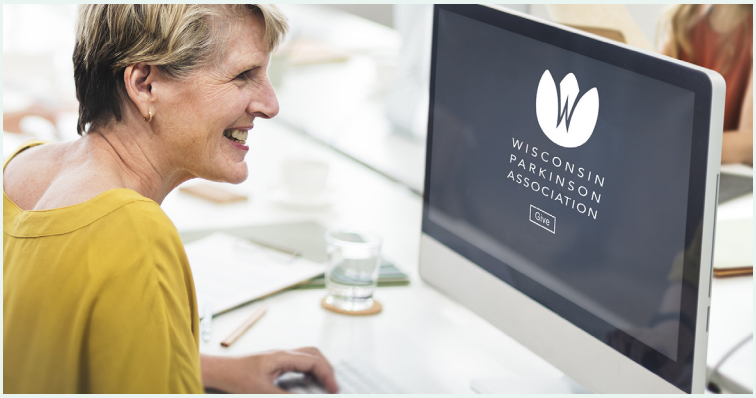
Connection Inspires Community

Navigating Parkinson's Together

— INSIDE —
STORIES OF SUPPORT & HOPE

In this Issue

Workplace Giving

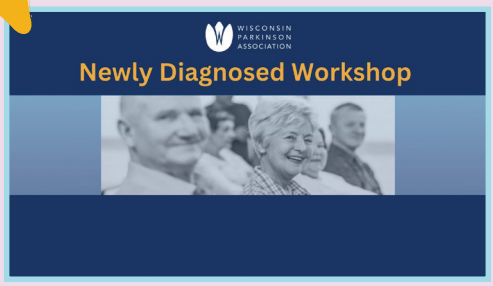


Make Your Giving More Impactful!

Does your company offer a matching gift program? Contact WPA at wiparkinson.org or 414-312-6990 to learn how your impact can double or even triple, sending hope further than you ever imagined.

New For You!

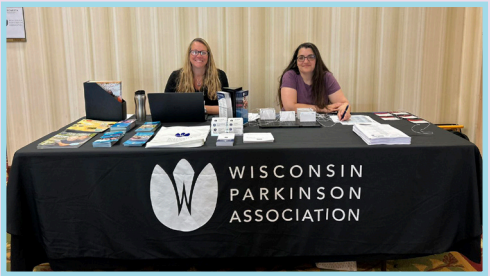
Wisconsin Parkinson Association Launches New Workshops



These workshops are designed for anyone navigating life after a Parkinson's diagnosis. These workshops welcome anyone seeking more clarity, education, or connection. Whether you're just beginning to process what Parkinson's means for your life or realizing you've never quite gotten the foundational information you needed, these workshops are for you!

Each workshop offers a comprehensive introduction to Parkinson's: what it is, how it's diagnosed and treated, and what therapies (physical, occupational, and speech) can help.

The workshops are held in partnership with WPA's Medical Advisory Committee, which includes movement disorder specialists and care team members from across Wisconsin.



You can find upcoming workshop dates and locations at wiparkinson.org.

Letter from the Executive Director

"Whether it's a conversation at one of our events, a shared moment of laughter, or hearing your stories of courage and resilience, I'm continually reminded of the strength and heart of this community."

One of the most meaningful parts of my role as Executive Director of Wisconsin Parkinson Association is the privilege of connecting with so many of you. Whether it's a conversation at one of our events, a shared moment of laughter, or hearing your stories of courage and resilience, I'm continually reminded of the strength and heart of this community.

Our 2025 WPA Symposium this spring was a wonderful time and place to connect with so many of you.

Living with Parkinson's, or caring for someone who is, can feel isolating. But connection changes that. When we come together, we create something powerful: understanding, support, and hope. This issue of the magazine is a celebration of those connections and the difference they make.

Inside, you'll learn more about our growing Young Onset Parkinson's Disease (YOPD) group, which is building strong networks and creating space for shared experience. You'll learn how a creative idea and a personal tribute turned into our very first and incredibly successful Yacht Rock fundraiser. And you'll hear from Coreen Dicus-Johnson of Network Health, who shares insight on surrounding yourself with the people and resources that help you live well with PD.

From rock climbing to Yacht Rock, this issue highlights the many ways connection builds strength, fosters inspiration, and helps people feel seen and supported.

Thank you for being part of this vibrant and compassionate community. I hope the stories in these pages encourage you to keep reaching out and making connections.

Wishing you a joyful and restorative rest of summer,

Kelly Cieslak, MBA, Executive Director
kellyc@wiparkinson.org | 414.312.6990

Your Donation Matters

"Every Contribution Creates an Impact."

Fundraising lies at the heart of nonprofit sustainability, enabling organizations like Wisconsin Parkinson Association (WPA) to fulfill our mission of supporting individuals with Parkinson's disease and their families. Ongoing support is absolutely vital to ensure critical resources like educational programs, community outreach, and member support continue to thrive and remain accessible without interruption. Fundraising efforts also ensure that WPA remains a trusted source for accurate information and advocacy within the Parkinson's community.

While fundraising efforts might be viewed as the work of the organization, WPA relies on the generosity of our donors to move our organization forward. It truly takes all of us working together to make this important work possible. We're reminded of a quote attributed to Margaret Mead: "A small group of thoughtful people could change the world. Indeed, it's the only thing that ever has." WPA has experienced many thoughtful people changing the world of those living with Parkinson's. Here is the story of one individual, Betty, who made a difference with her donation:

> *My husband was diagnosed with Parkinson's about two years ago. This past April there was a Facebook challenge about walking one mile a day for 30 days. I enrolled. My total mileage was 78. It was a struggle when I started. I wasn't a regular walker, now, I am.*
>
> *There were a number of people who sponsored me, and those donations are going to WPA. It's not much, but every bit counts. Enclosed is my check for $400.*
>
> *Sincerely, Betty*

As Betty reminds us, **every bit counts**.

Your donation matters and it makes a difference for those living with Parkinson's. WPA appreciates your support whether it be through annual, quarterly, or monthly giving options, or through creative individual fundraising opportunities like Betty's.

Fundraising is not merely a financial transaction; it is a testament to the shared commitment of individuals, families, and organizations to improve the quality of life for those living with Parkinson's. It's about thoughtful people doing what they can to change the world. WPA is fortunate that many people are willing to partner with us in this effort.

To make a donation, please scan the QR code or go to our website @ wiparkinson.org.

Finding His Voice:

Garry Meister's Journey with Parkinson's

"Garry realized the power of his voice extended beyond his own fight. 'If speaking up helps someone else,' he says, 'it's worth it.'"

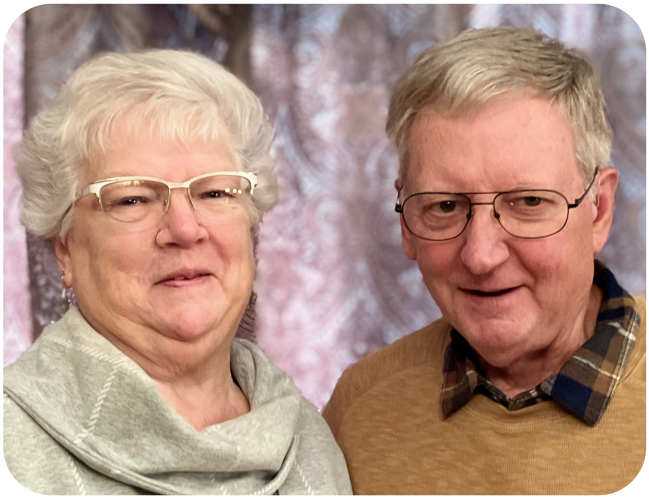
Garry Meister's first sign of trouble was a nagging cough during meals. It was subtle at first, easy enough to ignore, but it persisted. Weeks passed, and soon months slipped by without answers. He noticed other things: a tremor in his chin, a hand that shook slightly when he lifted a glass, and a once confident voice that had become little more than a whisper. Eventually, a neurologist delivered the diagnosis: Parkinson's disease.

Garry didn't spend time on questions like "Why me?" Instead, he focused on what came next. He set his sights on reclaiming his voice. Working with therapists, he joined the Loud Crowd, a weekly group dedicated to speech exercises. Garry learned quickly how Parkinson's distorts perception. "You think you're speaking loud enough," he says. "But really, you're just whispering." Week after week, he pushed his voice louder, clearer, stronger. He felt himself taking back control.

Speech therapy became the gateway to something more. One afternoon, another member of the group asked him directly, "Do you exercise? That's how you fight this." Garry had never been one to exercise, but the comment stuck with him. Soon he found himself driving to exercise sessions twice a week, 25 miles each way, to work with Joy Cochran, DPT, Owner of Joy Explorations. Garry affectionately calls her "the Drill Sergeant." "She pushes me harder than I thought I could go," Garry admits. "And I'm so glad she does."

The exercise sessions changed him, step by step. His golf game improved noticeably. Simple movements he had taken for granted returned to him. One afternoon, Garry knelt down on the living room floor and crawled alongside his great-granddaughter. It was a small moment, but it mattered deeply. It reminded him why he kept showing up.

Yet Garry also learned to accept that moving forward sometimes means asking for help. Initially, he resisted. Accepting help felt like a setback. But Garry gradually understood it as another step toward progress. At his side



through all of it was Nancy, his wife of nearly sixty years. "Nancy isn't just my support," he says. "She's my anchor."

Garry's momentum extended beyond himself. He found community in his Janesville support group, led by Connie Udell. Here, Garry shared openly, even about issues that were rarely discussed. After speaking about swallowing challenges at an event, a man approached him afterward. "You're the first person I've heard talk about this," the man said. "I have it too." Garry realized the power of his voice extended beyond his own fight. "If speaking up helps someone else," he says, "it's worth it."

Garry even tried kayaking, a challenge proposed by Joy Cochran. He climbed into a solo kayak, paddled away from shore, and felt every stroke reaffirming his strength. It was an active, deliberate moment of defiance against Parkinson's.

Today, Garry Meister isn't focused on heroics or perfection. He simply chooses to move forward, one deliberate step at a time. Parkinson's tried to slow him down, but Garry decided early on not to let it stop him. "Moving forward is my way of life now," he says firmly. "I won't let Parkinson's take that from me."

Building Strong Connections:

The Key to Navigating Parkinson's Care

Insights from Coreen Dicus-Johnson,
President and CEO of Network Health

Navigating life with Parkinson's disease can feel overwhelming, and no one should have to navigate it alone. At the heart of effective care lies something profoundly simple yet often overlooked: the relationships we nurture with our care teams and health insurance providers. These connections can transform the journey from feeling like an uphill battle to becoming a team effort.

WPA recently had the chance to speak with Coreen Dicus-Johnson, President and CEO of Network Health. She shared some valuable insights on the importance of developing strong connections with those who can provide support, encouragement, and guidance in your health care journey.

Coreen has spent her career witnessing the difference meaningful relationships can make in the health care experience. While she leads one of Wisconsin's most respected health plans, her perspective moves beyond policies and premiums. For Coreen, it's about fostering trust, understanding, and partnership between individuals, their health care providers, and their health plans.

"It's not just about the treatments or the medications," Coreen shares. "If we don't have a strong relationship with our care team and health plan, we're missing a critical piece of the puzzle. Health care isn't a transaction, it's a collaboration. That collaboration begins with trust, communication, and the belief that your voice matters."

Why Relationships Matter

At its core, health care is human. It's easy to get lost in the technicalities of appointments, medications, and insurance claims, but the foundation of effective care is built on connections. For those living with Parkinson's, these relationships are especially vital. Parkinson's requires an approach that adapts to individual needs, and no one knows those needs better than the people living with it every day.

A strong relationship with your providers means having a team that listens to you, understands your goals, and is genuinely invested in your well-being. Similarly, having a supportive health plan ensures that your care is not just about access but about advocacy, helping you navigate the system, find the right resources, and make informed decisions.

Coreen emphasizes, "If you don't feel supported by your health plan or your care team, it's okay to ask questions or even explore other options. You deserve care that not only meets your needs but empowers you."

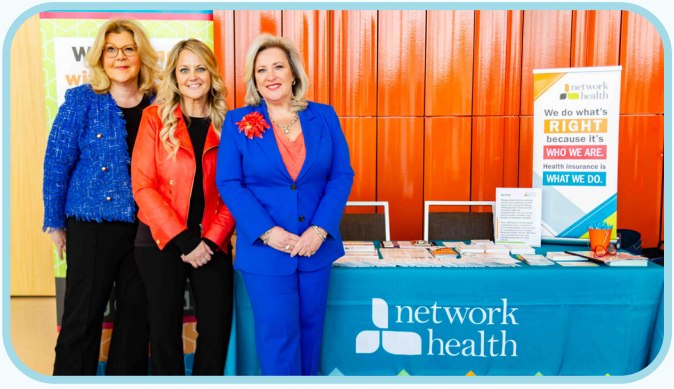
"If we don't have a strong relationship with our care team and health plan, we're missing a critical piece of the puzzle. Health care isn't a transaction, it's a collaboration. That collaboration begins with trust, communication, and the belief that your voice matters."

Partnerships in Practice

Building these relationships starts with clarity and communication. If conversations with your providers feel overwhelming or leave you with lingering questions, don't hesitate to ask for clarification. Open dialogue ensures that everyone is on the same page and working toward the same goals.

Another key component is assembling a care team that works together seamlessly. "Think of it as building a support system," Coreen explains. This could include a neurologist, a physical therapist, and even a social worker. Each person plays a role in contributing to your overall well-being, and their collaboration strengthens the holistic approach to your care.

Insurance providers, too, are a part of this equation. Coreen encourages people to think of their health plan as more than just coverage. "Your health plan should be a partner in your journey, helping you access the right care and remove barriers along the way."



(Left to right) Pat Boelter, President, Signature Services Group; Kelly Cieslak, Executive Director, Wisconsin Parkinson Association; Coreen Dicus-Johnson, President and CEO, Network Health at the WPA 2025 Spring Symposium.

Advocacy and Empowerment

Finally, Coreen underscores the importance of advocacy. If your current health plan or provider doesn't align with your needs, don't be afraid to explore other options. Finding the right fit is a step toward better care, better outcomes, and, ultimately, a better quality of life.

"We're all in this together," she says. "Whether it's your neurologist or your insurer, everyone should be part of the team that walks alongside you."

Moving Forward Together

Coreen's insights remind us that health care isn't a one-way street. It's about relationships; mutual trust, shared understanding, and working toward common goals. For those navigating Parkinson's, having a care team and health plan that stand with you can make all the difference.

As Coreen puts it, "It's not just about the care you receive, it's about the people who provide it. And when those people truly partner with you, it changes everything."

Take Coreen's advice to heart: advocate for the relationships and connections that truly support you. With the right team beside you, you can spend less energy navigating the system and more time living well with Parkinson's.

network health

Coreen Dicus-Johnson, Network Health, President and Chief Executive Officer (CEO)

Coreen Dicus-Johnson is President and CEO of Network Health, a Wisconsin corporation offering commercial and Medicare Advantage health insurance plans for employers, individuals and families, where she dedicates herself to the organization's mission of building healthy and strong Wisconsin communities. A passionate community leader, she has spent over 25 years supporting organizations that improve lives across Wisconsin and serving on over 20 nonprofit boards. Coreen earned her undergraduate degree from Marquette University and a Juris Doctor from DePaul University College of Law.

Reaching New Heights:

How Rock Climbing is Elevating the Parkinson's Community

Ron Scherr wasn't sure what to expect when he heard about WPA's upcoming rock-climbing event at Adventure Rock. At 76 years old, diagnosed with Parkinson's in 2015, he'd tried to stay active by bowling in the winter, golfing in the summer, attending a WPA-sponsored exercise class at his local senior center. But this? This was different.

Still, he showed up and he brought his grandsons.

"I wanted to challenge myself," he said. "I wanted to show them I could do it."

That afternoon, as cheers echoed through the climbing gym and Ron scrambled confidently up three different walls, something powerful happened, not just to Ron, but to everyone watching. His grandsons beamed. His wife Renee took videos, cheering louder than anyone. Later, Ron joked that he'd become a bit of a celebrity, having been featured on the evening news.

"I went up that wall like a spider," he laughed.

However, behind that feeling of lightness was something deeper: a spark of confidence, joy, and purpose. "It was emotional," Renee said. "Seeing him up there, doing something none of us imagined. You could see the sense of accomplishment on his face."

That's exactly the kind of transformation Sam Szyjakowski had in mind. Sam has been with Adventure Rock since the beginning, balancing a 30-year aviation career with his passion for instruction. Eleven years ago, an adaptive program was created to serve people who had spinal cord injuries, autism, Down syndrome, and more recently, those living with Parkinson's.

"My great-grandfather had Parkinson's," Sam said. "Back then, there wasn't much they did. When I started reading about how many people love Rocksteady Boxing, I thought, why not climbing?"

So he reached out to WPA, and the idea took flight.

What started as a single trial session has become one of the most popular and inspiring programs WPA offers. Volunteers are plentiful too, many of them physical therapy students from local universities like Marquette, Carroll, and UWM who want to make a difference.

"We have approximately 50 volunteers," Sam explained. "Without them, the program wouldn't be what it is today. They show an amazing dedication to helping others."

"Some people arrive saying, 'I don't think I can do this,'" Sam said. "But we've got workarounds for every movement challenge. We've got support. Most importantly, we've got a room full of people who believe in you before you believe in yourself."

Each climber is paired with at least one "side climber" for support and encouragement. The goal? Not just to reach the top, but to feel safe, seen, and strong every step of the way.

"The thing that surprised me most," Sam said, "was how many people with tremors saw those tremors diminish during the climb. Not disappear, of course, but lessen. The look on their faces when they realize they can do something they didn't think was possible? That's everything."

From the moment participants walk in the door, the experience is built to calm nerves and build trust. "Some people arrive saying, 'I don't think I can do this,'" Sam said. "But we've got workarounds for every movement challenge. We've got support. Most importantly, we've got a room full of people who believe in you before you believe in yourself."

There's even a bell at the top of a few routes. When a climber reaches it, they give it a ring, and the whole gym erupts in cheers. The cheers aren't just from fellow climbers, but from strangers, families, staff, and volunteers. It's an electric environment brimming with hope and accomplishment!

What Ron remembers the most is the feeling of doing something bold, unfamiliar, and hard, and doing it well.

"Afterwards, I knew I could do it," he said. "That confidence stays with you."

That's the ripple effect of programs like this one. Confidence leads to courage. Courage leads to momentum. And momentum, for someone living with Parkinson's, can change everything.

"We hate to see people walk away without trying," Sam said. "Fear fades. Regret doesn't. If you try it and it's not your thing, fine. But more often than not, people surprise themselves. They climb higher than they ever thought possible."

That afternoon at Adventure Rock, Ron climbed not just for himself, but for his grandsons. For Renee. For everyone who's ever wondered if their diagnosis means the end of daring adventures.

He climbed to prove that it doesn't.

Kelly Cieslak, WPA's Executive Director also attended the event and had this to say, "At WPA, we encourage people with Parkinson's to live their best lives and stay moving, so bringing something new like this to our community was incredibly rewarding. It was emotional and empowering to see people push past their limits and support one another, truly a top-tier mission moment. We're excited to expand our partnership with the amazing team at Adventure Rock."

A Day About Living:

How Yacht Rock Became a Celebration of Life, Legacy, and Community

By the time the band hit the stage, the dance floor at Matty's was already full, smiles as bright as the afternoon sun, arms wrapped around old friends, strangers moving in rhythm like family. This wasn't just a concert. It was a reunion. A tribute. A movement. For Kristi Wieland Guthrie, it was also a promise kept.

Her mother, Joan, lived with Parkinson's disease for 38 years. She passed away in January 2020 after a long and courageous battle. Kristi was in fourth grade when her mom was diagnosed, and as an adult, she became Joan's primary caregiver, supporting her through the day-to-day realities of a disease that slowly changes everything.

After the funeral, after the caregiving ended, grief settled in like a fog. "I needed time to sit in it. I needed time to heal," she said. Then, in the quiet, a voice emerged, faint at first, but insistent. Her mother's voice. "We need to throw a party."

Not a somber memorial. A party that would honor Joan's spirit and bring people with Parkinson's together. A party that would celebrate life, not in denial of Parkinson's, but in defiance of it.

That idea, sparked by love and grief and music, became Yacht Rock, a daylong event in support of the Wisconsin Parkinson Association. Together with her best friend and WPA board member, Angela Pecoraro, Kristi set out to throw a fundraiser that felt like anything but.

"I just kept thinking about my mom and what she loved," Kristi said. "She loved live music. She loved people around her. This had to feel like her."

They chose Yacht Rock: upbeat, nostalgic, multi-generational music that gets people dancing. And they made sure everything about the day reflected their mission: To celebrate

"I had never done a fundraiser before," Kristi admitted. "WPA backed me up. The team members partnered with me and said, 'We believe in you.' That meant everything."

those living with Parkinson's, honor caregivers, build community, and raise awareness for WPA.

Held at Matty's The Big Backyard in New Berlin, the event included a movement clinic led by WPA partner, Susanne Carter (because, as Kristi reminded everyone, exercise is one of the best ways to slow the progression of Parkinson's). There was a painted tree set up near the entrance, where guests were invited to add a fingerprint leaf, each dab of color a symbol of their place in a growing, supportive community. There were raffle prizes, silent auctions, and a table full of beautiful, handmade blankets donated by Dawn Jourdan, a friend of WPA whose father had PD.

"I had never done a fundraiser before," Kristi admitted. "WPA backed me up. The team members partnered with me and said, 'We believe in you.' That meant everything."

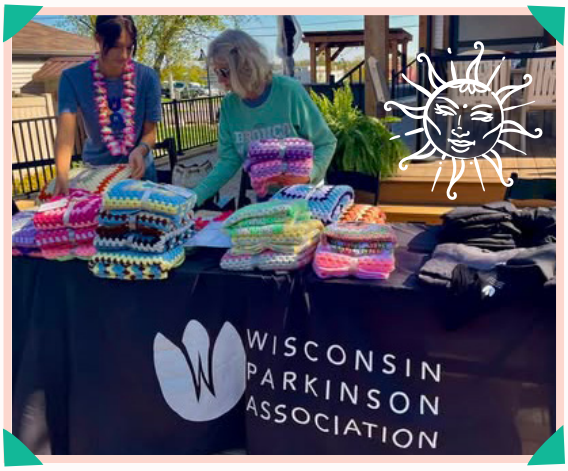
Angela brought her event planning experience and her passion for WPA to the project. She's served on the board for four years and saw this event as more than just a fundraiser. "It was about expanding our reach," Angela said. "If we could touch just one new family, connect one more person to the resources WPA offers, that would make it all worth it."

They sold over 300 tickets. People flew in from all over the country. Families came together, caregivers showed up in droves, and more than 40 volunteers helped make the day run smoothly. With all that being said, the most powerful moments weren't logistical, they were emotional.

"My fourth-grade teacher came," Kristi said. "She knew my whole family. She knew my mom. She came to honor her. I looked around that day and I saw smiles everywhere. Hugs, laughter, dancing. People being goofy."

"We introduced so many new people to the organization," Angela said. "People left knowing that WPA exists, what it stands for, and how it helps people live their best lives. That's what the day was about, LIVING, not struggling."

For Kristi, it was also about transformation, of grief into action, of memory into movement. "I call it part of my healing journey," she said. "Turning loss into something positive. Keeping my mom close but also moving forward."



The event raised $55K, more than they ever expected. Yet, as both Kristi and Angela are quick to emphasize, this was never just about dollars.

"It's about showing people with Parkinson's they're not alone," Kristi said. "It's about giving caregivers a village. It's about saying: come out, join us, live fully. You don't have to hide."

Tentative plans are already forming for next year's Yacht Rock. However, to make it happen, they'll need help. "We pulled this off with just our families and a few amazing friends," Angela said. "We're looking for new committee members, people who can help with marketing, logistics, raffles. We've got the playbook. Now we just need the team."

Anyone interested in helping can contact WPA at wiparkinson.org

After the Shock:

Finding Clarity in Parkinson's Workshops

"These workshops are for anyone living with Parkinson's who wants to feel more informed, more connected, and more empowered," Dacy says. "It doesn't matter when the diagnosis came, what matters is what happens next."

When someone is diagnosed with Parkinson's disease, the moment can feel like a hard stop. Shock. Fear. A hundred unanswered questions. And for many, the most pressing one: Now what?

Wisconsin Parkinson Association's newly launched Parkinson's Workshops aim to answer that question and more.

The workshops were created in response to a growing need. "We realized there was a gap in support right at the time of diagnosis," says Dacy Reimer, WPA's Director of Medical Advising and Education. "People were either getting too much information at once or not enough, and either way, they were overwhelmed. We wanted to give them something grounding. Something human."

These workshops are designed for anyone navigating life after a Parkinson's diagnosis, not just those newly diagnosed last week or last month. Many participants received their diagnosis within the past five years, but the sessions welcome anyone seeking more clarity, education, or connection. Whether you're just beginning to process what Parkinson's means for your life or realizing you've never quite gotten the foundational information you needed, these workshops are for you.

Each workshop offers a comprehensive introduction to Parkinson's: what it is, how it's diagnosed and treated, and what therapies (physical, occupational, and speech) can help.

What tends to leave the most lasting impact, however, is the lived experience panel.

"The lived experience panel is my favorite part," Dacy says. "We bring up three individuals with Parkinson's who talk candidly about the day they were diagnosed, how they processed it, and what they've done since. Their stories are so different. Some went to bed for two weeks, some sprang into action. Despite their differences, all of them found a way forward."

That diversity of experience is at the heart of the program's message: no two people are alike with Parkinson's. The workshops don't offer a one-size-fits-all roadmap. They offer real tools, real stories, and a reminder that there is no wrong way to walk this path.

Participants also hear from movement disorder specialists, neurologists, and their care teams who generously donate their time. These experts not only present clinical information but make themselves available to answer questions in an approachable setting. "It's powerful," Dacy says. "For many attendees, it's the first time they've spoken directly with a specialist or even met someone else with Parkinson's."

Just as important is the chance to connect. "Many attendees come in feeling isolated," Dacy says. "Some haven't told anyone about their diagnosis. Some don't know another soul with Parkinson's. By the end of the day, many have met others like them, discovered where the local support groups are, and finally put faces to facilitators' names.

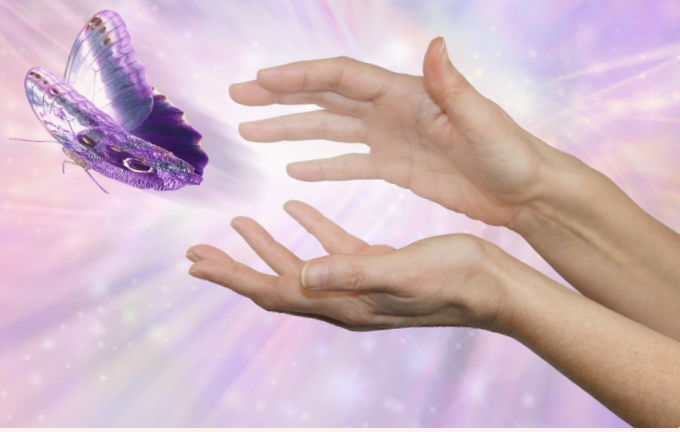
The workshops are held in partnership with WPA's Medical Advisory Committee, which includes movement disorder specialists and care team members from across Wisconsin.

"These workshops are for anyone living with Parkinson's who wants to feel more informed, more connected, and more empowered," Dacy says. "It doesn't matter when the diagnosis came, what matters is what happens next."

For upcoming workshop dates and locations, visit wiparkinson.org.

Decision Crossroads:

Hospice Care



By: Lisa Kokontis, MD, Neuroscience Group, Neenah
WPA Medical Advisory Committee Member

There can come a time during a chronic health condition where treatment is no longer tolerated or effective. Sometimes, other medical conditions can compete with the treatment of one condition and the quality of one's life can be compromised. If you find yourself at this crossroads, consider palliative care to be an option to help sort out goals and limits of care, as well as add an additional layer of support and guidance.

The palliative care team can include RNs, physicians, social workers, and a member of your religious order. The physicians specializing in palliative care are well versed in chronic health conditions and can be family practice or internal medicine specialists with additional training in symptom management, communication and advance care planning. They often work within your healthcare team to provide comprehensive care for people with serious illnesses.

The professionals of a palliative care service approach your conditions with a focus on improving quality of life by addressing your physical, emotional, social and spiritual needs. Symptom management can include effective pain relief, sleep quality, developing a strategy for troublesome bowel or bladder symptoms or any other physical symptoms that affect your day-to-day function. They will work alongside your Parkinson's provider to help you get the most from your medical regimen. Sometimes, I find people on an incredibly long list of medications that accumulate over the years. Palliative care providers have a knack to trim back this list according to your medical goals.

It is important to discuss advanced care planning to ensure that your future care aligns with your preferences. This discussion can help clarify decision making for you and your family and can greatly reduce stress in an urgent situation. The team also supports emotional and social needs and can offer spiritual support as well.

Palliative care and hospice care both focus on improving quality of life for patients with serious illnesses but they differ primarily in timing of eligibility criteria and treatment goals.

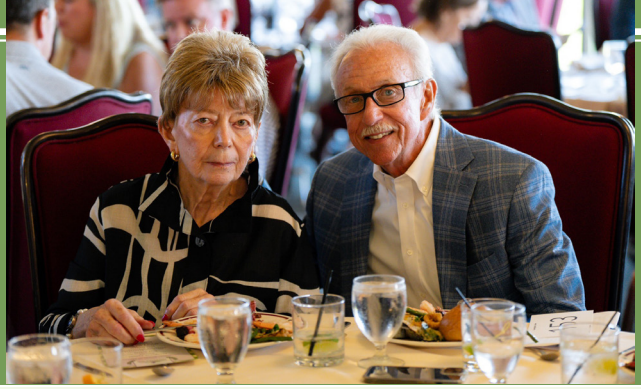
Palliative care can be provided at any stage of a serious illness alongside curative or life prolonging treatments and aims to improve quality of life by managing symptoms, providing emotional and social support and assisting with advanced care planning while still allowing for curative treatments.

Hospice care focuses on comfort and quality of life at the end of life, emphasizing symptom relief and emotional support without curative intent. It is typically provided in a person's home or specialized hospice facility to maximize comfort and avoid hospitalization. Hospice teams also involve RNs, physicians, social workers and spiritual care professionals.

Many people feel that they do not need their services "yet." My experience is that most families wish they had asked for their input earlier. Both palliative and hospice teams offer incredible support and guidance that can be transformative for your journey through Parkinson's disease. Reach out to your health care provider to request a palliative or hospice consultation.

What Love Tees Up:

The Story Behind the Cosentino Family Parkinson's Open



When Dick Cosentino's wife, Patty, was diagnosed with Parkinson's, life changed in an instant. That moment in the doctor's office became a turning point, one of those quiet, irreversible moments that divide life into "before" and "after." As the doctor spoke, the air felt heavier. There were questions with no clear answers, fears they hadn't prepared for, and a future that no longer looked the way it once had. However, even in that wave of uncertainty, one truth emerged with perfect clarity: from that day forward, it wasn't just Patty's diagnosis. It was their journey. It was a shared promise to face whatever came next, side by side.

Fifteen years later, that same spirit of togetherness echoes across the fairways of Westmoor Country Club. Inspired to take action, Dick came up with the idea of hosting a golf outing, something that could bring people together, raise funds, and honor Patty's journey. What started as a personal mission quickly grew into a powerhouse of purpose.

Under Dick's leadership, the event has grown significantly, with total funds raised over three years expected to surpass $1 million. The Cosentino Family Parkinson's Open helps support programs like rock climbing, mindful movement classes, educational workshops and support groups, podcasts and the annual educational symposium.

"It's not about one person," Dick says. "It's about community." That community includes the dedicated committee behind the outing, the golfers who show up year after year, and the countless families who rely on the WPA's resources, often free of charge, to help navigate life with Parkinson's. Dick, now chair of the WPA board, sees firsthand the impact of every dollar raised. "You might think you're just hitting a ball on a sunny day, but you're changing lives."

For Dick, caregiving is a privilege. He's given up a lot, but he's gained something deeper: a sense of purpose, perspective, and love that still makes him laugh with Patty every day. "She's never complained. Not once," he says. "We still love each other after 55 years, and we still laugh." That spirit, humble, hopeful, and quietly heroic, is what fuels the Cosentino Family Parkinson's Open and everything it stands for. It's a celebration of resilience, of love in action, and of the power of showing up for one another, no matter what.

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Benefiting the Wisconsin Parkinson Association

Monday
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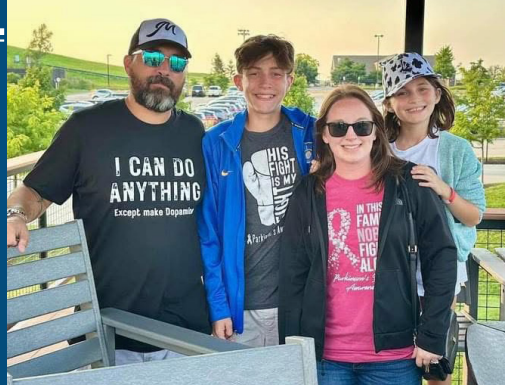
We're Here Too:

How Carlos Is Leading a Movement for Young-Onset Patients



"There's no roadmap," Carlos says. "No guidebook for what it looks like to be 36 with Parkinson's—with a mortgage, kids, and a career that's still climbing."

Carlos Arnold was 36 when his world shifted.

Not with a loud crash, but with the quiet weight of a Parkinson's diagnosis. He was young, too young, it seemed, for a disease he had always associated with people decades older. One minute he was chasing deadlines at work, cheering at his son's baseball games, and managing the chaotic joy of family life. The next, he was wondering how to keep doing all that with a body that, some days, didn't want to cooperate.

"There's no roadmap," Carlos says. "No guidebook for what it looks like to be 36 with Parkinson's—with a mortgage, kids, and a career that's still climbing."

In the early days, he looked for community, anyone who might understand the peculiar challenges of Young-Onset Parkinson's Disease (YOPD). Most support groups leaned older, and while the stories they shared were powerful, they didn't speak to his situation, now: the pressure of providing for a family, the fear of what symptoms might mean five, ten, twenty years down the line.

So, when Dacy Reimer from the Wisconsin Parkinson Association reached out about launching a support group specifically for young-onset patients, Carlos didn't hesitate. "It was something I needed," he says. "And if I needed it, I knew other people did too."

The group met virtually for the first time just a month later. Twenty-two people logged on, some newly diagnosed, some years into the journey. One man was in the middle of his diagnostic process that very week. "You could see the weight lift off his shoulders," Carlos says. "That's when I knew that this matters."

It matters because young-onset Parkinson's brings its own vocabulary of hardship. There's the tremor, sure, or in Carlos's case, the stiffness and dragging gait that make mornings longer and parenting more exhausting. There's also the invisible load: trying to explain a diagnosis to a confused child, weighing whether to tell your boss, wondering how to save for college and a future of rising health care needs.

"There's a different kind of grief," Carlos says. "You're still living your life. You're supposed to be building your future, and now there's this thing you carry through every part of it."

However, the group doesn't just dwell in hardship. It's a space for honesty and humor, for late-night venting and early-morning pep talks. They've created a list of questions, things they wish they'd known to ask at diagnosis. They swap ideas about doctors, diet, exercise. They remind each other it's okay to have challenging days.

"I always tell my family, 'I'll deal with Parkinson's when I'm older,'" Carlos says with a chuckle, but beneath his humor is grit. "I just keep going," he says. "Every day, I support my family, I work, I show up for my son's baseball games, I exercise and I eat better. That's how I fight."

Carlos is quick to remind others they're not alone in the fight. Thanks to WPA, YOPD patients across Wisconsin can now log into a monthly Zoom call, co-facilitated by Carlos, Wendy Sorem and Stephanie Johnson and find their people. There's even a couple of women's YOPD groups led by Wendy in Appleton and Stephanie in Madison expanding the network of understanding and care.

"If I can help just one person climb out of a dark place and realize they're not alone, then it's all worth it."

In the end, this group isn't just about Parkinson's. It's about showing up, for each other, for ourselves, for the lives we still get to live. It's about saying: we're here too, and we're not going anywhere.

To learn more or join the Young-Onset Parkinson's support group, visit wiparkinson.org.

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